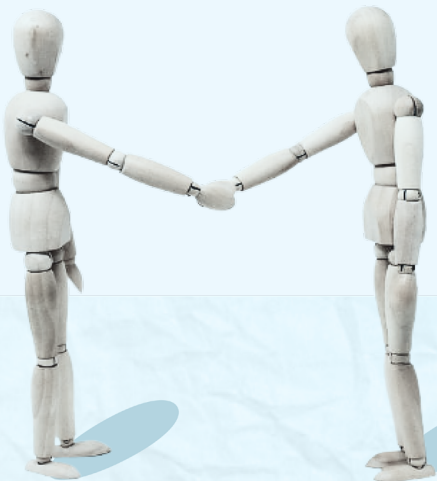*Designing to Include*

Dementia & Personhood

A resource for *designers* and *developers* who are creating inclusive products for people living with dementia.

Version 1.0

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We Can and Should

- Create inclusive products for people living with dementia.

- Complement and respect personhood with these products.

- Include people living with dementia in the process.

The Challenge & Opportunity

The Challenge
As our population ages, the number of people with dementia rises. However, products are often not built to reflect what people living with dementia want and can use.

The Opportunity
People living with dementia have great ideas from their lived experience. Designing with them means your technology will be more intuitive and ultimately more accessible to a wide range of people.

Key Definitions

What is Dementia?
Dementia is an umbrella term used to describe symptoms caused by changes in brain function that impact a person's abilities and behaviours. Every person with dementia is unique and can live well after their diagnosis.

What is Personhood?
Personhood is the qualities that make up who we are as a person, such as our values, beliefs, and sense of self. Personhood is as distinct and important to people living with dementia as it is to anyone else.

Before you get started

At its core, designing for people living with dementia is no different than designing for anyone else. You need to build background on the topic, engage directly with end-users, and continue to iterate on your product and process. We highlight the idea of personhood because it's often forgotten in the jumble of clinical terms and pages upon pages of accessibility guidelines.

Designing to reflect personhood really just means designing for people—people with values, beliefs, and a sense of self. People who want to have fun, form relationships, and live life to its fullest. The process may be challenging at times and will often require more flexibility and patience. However, the impact you make in this emerging field will be meaningful and well worth the effort!

Key mindsets

Creating great solutions that address real problems requires collaboration with end-users—this doesn't change when designing for dementia. You need to engage with people living with dementia, as well as their family, friends, and formal care partners. To reflect personhood, both your process and product should foster feelings of mastery, respect and competence, and help individuals live a good and meaningful life with dementia. Here are some key mindsets that will help you design to reflect personhood:

Nothing For Us Without Us
People living with dementia are experts on what it's like to live with dementia. Instead of building what you think they need, collaborate with people who have lived experience to create real solutions together.

Build Background
Learn about the people you are designing for in a non-clinical way. Spend time volunteering or engaging with autobiographical resources to learn about different individuals and their unique journeys.

Foster Trust
Trust is essential when working in this space. Building trust with individuals as well as organizations will help you connect to stakeholders, explore ideas, and get honest feedback.

Dementia is Dynamic
People living with dementia's abilities can change day to day and sometimes hour to hour. Never make assumptions based on a single interaction.

Be Patient
Give people time and space to gather and express their thoughts. Don't make people feel rushed or pressured when things don't go as planned. Fight the urge to fill thoughtful pauses.

Budget Extra Time

Extra time and consideration are required at every step. You need time to foster trust and iterate, not only on the product but on the process itself.

Be Flexible

There is no one size fits all solution—this is true for the process and the product. You will need to assess and adapt your design methods to complement the needs, abilities, and attitudes of people living with dementia. Be prepared to tweak your approach for each individual.

Be Open-Minded

Throw your biases and assumptions out the window about who people are and how they use products. Commonly used features such as swiping, clicking, and scrolling are not intuitive to everyone.

Be Respectful

People living with dementia are people with thoughts, feelings, and dignity—they deserve to be treated with respect.

User Recommendations

Before The Discussion
- Foster trust by being kind and courteous to individuals with dementia and other stakeholders you work with. Consider volunteering for programs or activities to show your commitment to this community.

- Be flexible on where and how you work together. Let the person with dementia choose the time and place whenever possible.

- Get clear, informed consent. Explain verbally and in writing what the person will be asked to do and give them time to consider and ask questions.

- Enable people to come prepared. Send information that gives an overview of what the person will be asked to do, when it will happen, and where it will happen. Ask the person how often and how they would like reminders.

During The Discussion
- Create a comfortable environment that's quiet and free of distractions.

- Encourage genuine responses by acknowledging and respecting the person living with dementia as the expert of their own lived experience.

- Speak clearly and only ask one question or directive at a time.

- Engage in active listening; show people living with dementia you are interested and value their perspective.

- Be prepared for unconventional or unexpected vocabulary and try to clarify what they mean. Think about and adapt the way you communicate; not the other way around.

- Don't be afraid to ask questions to dig deeper into why people are saying what they're saying.

- Show people what you mean with clear examples such as pictures and working prototypes.

<u>After The Discussion</u>

- Treat people living with dementia with the same respect you would give to anyone who shares their time and knowledge with you.

- Include the names of people living with dementia in your work; make sure you ask for their consent.

- Compensate people living with dementia for their time. If they cannot accept direct payment, you can also allow them to choose a charity to donate to.

Design Recommendations

Information architecture
- Keep navigation linear and reversible to show users where they are and allow for misclicks.

- Be consistent in the use of colours, words and information flow to help orient users.

- Sequence content into smaller chunks so it's easier to digest.

- Only have one task per page whenever possible to support focus and reduce noise.

Interaction design
- Allow for customization and personalization to support accessibility and to enable people living with dementia to express who they are.

- Incorporate user interface patterns that people living with dementia might already be familiar with.

- Make sure all controls are visible and obvious. Avoid hidden elements or implied controls like scrolling and swiping.

- Make it clear what to do next and indicate when tasks are completed.

- Talk to your user groups about how they would like to interact with the technology (ie. voice activated).

Visual design

- Keep it simple. A lot of the time, less is more.

- Design in a way that is highly accessible for everyone, such as using high contrast colours, large, sans-serif fonts, and a clean layout.

- Tie a component's real-world function to its appearance. For example, give buttons depth so they look clickable.

- Use straightforward and mature designs. Designs can be fun but don't create childish designs for adults with dementia.

- Don't assume other designs for dementia have done it well; this is still an emerging area and not everyone gets it right.

These tips only scratch the surface of accessible design for people living with dementia. On top of direct engagement with these individuals, our final recommendation is to use various best practice guidelines such as the [Web Content Accessibility Guidelines (WCAG)](#) and the [Dementia Digital Design Guidelines/Heuristics](#).

How to Get Started

An important consideration when designing for dementia is the time needed to build trust with this community. You'll need time to build your background knowledge, but you should start building bridges right away. Here are some resources and general contacts to help you get started.

Building Background
- Learn about dementia from people who are living with dementia through the By Us For Us Guides.

- Change the way you view dementia and how to support people living with it through the Living the Dementia Journey.

- Learn how to use dementia-friendly language through Dementia Language Guidelines, Person-Centered Language Guidelines, and Person-Centered Language.

Building Bridges
When reaching out to organizations/individuals, keep in mind that they are busy. Make sure you know what value you're providing before you contact them. Ask yourself—what's in it for them?

- The Alzheimer's Society

- Research organizations

- University professors

- Local long-term care homes

- Local senior community groups

- Facebook groups, Reddit threads, personal blogs

Designing to Include Dementia & Personhood (End)

<u>The Backstory</u>

As researchers, developers, and designers, we entered this field and quickly discovered there were limited resources supporting the development of products with persons living with dementia as key stakeholders in the process. Too often, people living with dementia are not involved, resulting in poorly designed products that do not reflect or respect personhood.

This resource is a culmination of various lived experiences and research done by student designers and developers, academic researchers, industry leaders, and several individuals living with dementia. Ultimately, we hope this resource will encourage more collaborative projects that result in products that people living with dementia actually want and can use.

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Quotes

- "I'm still me!" (Brian, a Bit of Brian's Brilliance)

- "I need your empathy and understanding. Not your assumptions." (Roger Marple, A Person Living with Alzheimer's)

- "Doing whatever I can to reduce stigma and have a purpose-filled life." (Jay Reinstein, A Person Living with Early Onset Dementia)

Sources

Dementia - World Health Organization (WHO)

Inclusive Design - Microsoft

I'm Still Me! - A Bit of Brian's Brilliance

Living Well With Dementia - Alzheimer Society

Dementia Digital Guidelines/Heuristics - Alzheimer Society

Web Content Accessibility Guidelines (WCAG) - W3C WAI

Dementia language guidelines - Dementia Australia

Person-Centered Language Guidelines - Alzheimer Society

Painted images were created by various talented individuals living with dementia. Images were taken from Pexels, Unsplash and Flickr.